

State of Hawaii  
Department of Health

Child and Adolescent  
Mental Health Division

# **Population and Service Characteristics of Youth with Schizophrenia-spectrum Diagnoses in the Hawaii System of Care**

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**Abstract**

Examined the population and service characteristics of youth between 3 and 18 years of age receiving mental health services through the Hawaii Child and Adolescent Mental Health Division (CAMHD) during the period from July 1, 2000 through June 30, 2001. Youth with a diagnosis in the schizophrenia-spectrum ( $n = 71$ ) were compared to all other youth ( $n = 13,904$ ) who received services during the study period. Results indicated that these groups did not differ in gender or geographic distribution, but that the schizophrenia-spectrum group was older, had a higher Asian representation, more comorbid diagnoses, a higher proportion of youth diagnosed with mental retardation, and lower proportions of youth with disruptive behavior, attention, or adjustment disorders. Service analyses found that a higher proportion of youth with schizophrenia-spectrum diagnoses received out-of-home, intensive home and community based, and flex or respite services, but that when these services were provided they tend to be of a similar duration and intensity for youth with and without diagnoses in schizophrenia-spectrum. On the other hand, almost all youth (95%) in both groups received less intensive services, but youth in the schizophrenia-spectrum group received more treatment services at a higher intensity or longer duration than youth in the non-spectrum group. Although youth with schizophrenia-spectrum disorders are not common, as a group they are at an above average risk for out-of-home placement and consume resources at an above average rate.

## **Introduction**

### **Schizophrenia Among Children and Adolescents**

Schizophrenia among young people is a devastating and costly mental illness. Although the disorder is rare, interest in schizophrenia in youth has grown as researchers and clinicians recognize the benefits of understanding the disorder. Continued research promises to increase the ability to diagnose and treat early forms of schizophrenia, and possibly provide useful information about the etiology and course of adult-onset schizophrenia. Despite growing interest, however, research on schizophrenia among children and adolescents is limited. Several research groups currently pursue studies on individuals with early schizophrenia to discern functional and structural deficits associated with the disorder (e.g., Asarnow & Asarnow, 2003). While ongoing research continues to increase our understanding of biological and environmental factors associated with, and contributing to, the disorder, the rarity of the condition has resulted in only modest gains of understanding. Although youth with schizophrenia are seen in the community, factors such as basic demographics, services received, and cost of services remain areas of relative mystery. Increased knowledge of the demographic portrait of and services provided to children and adolescents with schizophrenia-spectrum disorders may increase general understanding and have implications for mental health care provision and legislation.

### **Prevalence of Schizophrenia Among Youth**

Very few studies have tracked rates of schizophrenia among youth in the general population. A study in North Dakota looking at children ages 2 to 12 did not find any instances of schizophrenia. Gillberg and Steffenburg (1987) estimated very early onset schizophrenia rates at 1.6 per 100,000 in western Sweden. Among slightly older youth receiving psychiatric outpatient services, Evans and Acton (1972) reported that the rate of psychosis was

approximately 1%. Remschmidt and colleagues (1994) suggested that approximately 1 in 10,000 children develop schizophrenia before 18 years of age. Additional epidemiological reports are needed to augment our current understanding of schizophrenia among youth. Overall, Asarnow and Asarnow (2003) note that current “prevalence figures must be viewed as highly tentative until more representative data become available.”

A study by Thomsen (1996) looked at childhood and adolescent onset schizophrenia throughout Denmark from 1970 to 1993. Findings indicated that only 32 children younger than 15 met criteria for schizophrenia between 1970 and 1993; comprising .86% of the psychiatric in-patient population. The occurrence of schizophrenia, however, increased with age. Between ages 15 and 17, 284 adolescents with schizophrenia were hospitalized from 1970 to 1993. Although informative, this study did not include youth served in non-hospital settings and did not include use of a broad diagnostic definition that included children and adolescents with schizophrenia-spectrum disorders. Given a trend towards least restrictive care in the United States, many children and adolescents with schizophrenia likely receive treatment in non-hospital settings. Schizophrenia-spectrum *disorders* may be of particular interest to researchers and clinicians because they are genetically linked to schizophrenia and may be more commonly diagnosed in young people to avoid the more stigmatic label of full schizophrenia (Thomsen, 1996). Assessing children and adolescents more broadly (e.g., including schizophrenia-spectrum diagnoses seeking services through both hospitalization and community clinics) may provide a more complete representation of early psychosis.

### **Systems of Care in Hawaii**

Developments within the public mental health system of Hawaii have provided a unique opportunity to describe the characteristics of, and public mental health services for youth with

schizophrenia-spectrum disorder. Two federal lawsuits have played an important role in the development of children's services over the past decade. First, in 1991, the State of Hawaii settled a class action lawsuit with the U. S. Department of Justice for violations of the civil rights of individuals residing at Hawaii State Hospital. Because youth were residing at Hawaii State Hospital at that time, the Department of Health's Child and Adolescent Mental Health Division (CAMHD) participated in the lawsuit. Second, in 1994, due to a failure to provide necessary mental health and educational services as required by the Individuals with Disabilities in Education Act (IDEA) and Section 504 of the Rehabilitation Act, the Federal Courts enjoined the State of Hawaii Departments of Health and Education in the Felix Consent Decree. The State was charged with establishing a system of care to provide effective mental health and special education services for children and youth in need of such services to benefit from their education. As a result, the last decade witnessed sweeping statewide systems reform.

The response to these lawsuits yielded large increases in the number of youth accessing services, the amount and type of services available, and the monitoring of system performance (e.g., Daleiden, 2002; 2003). Under the early design of the system, a comprehensive array of services from outpatient to residential placements was provided through CAMHD. Since the 2000 to 2001 fiscal year, the system of care has evolved into a school-based behavioral health model in which educationally related outpatient and less intensive services are provided through the Department of Education. More intensive mental health services are provided through CAMHD. Examination of data obtained just prior to this reorganization creates an opportunity to describe the youth and services provided through a comprehensive continuum of care. This analysis may serve as a baseline against which subsequent years may be compared to determine how services for youth were altered by the system reorganization.

## Current Study

The purpose of this study was to present demographic and services summary for consumers (under age 18 years) with a schizophrenia-spectrum disorder (schizophrenia, schizophreniform, schizotypal personality disorder, schizoaffective disorder, delusional disorder, paranoid personality disorder, brief psychotic disorder) registered with CAMHD during fiscal year 2001 (July 1, 2000 to June 30, 2001). We report on the more inclusive *schizophrenia-spectrum disorders* (including schizophrenia) rather than solely *schizophrenia* as spectrum disorders are genetically linked to schizophrenia and may be more commonly diagnosed among children in an effort to avoid stigma associated with the label “schizophrenia.” Additionally, this study compared the characteristics of, and services received by, children and adolescents with a schizophrenia-spectrum diagnosis to all other youth receiving services from CAMHD. This report attempts to provide useful demographic and service information regarding this poorly understood group of youth. We report descriptive information including age, gender, ethnicity, comorbid diagnoses, level of service, and cost per youth for individuals with a schizophrenia-spectrum disorder. Additionally, we compare these factors for the youth with spectrum disorders to all other youth registered with CAMHD.

## Methods

### Participants

Participants for this study were all youth under 18 years of age as of June 30, 2002 who were registered with CAMHD for one or more days during the period from July 1, 2000 to June 30, 2002. The total sample of 13,975 youth was divided into two groups based on the presence versus absence of a schizophrenia-spectrum disorder. Specifically, 71 youth (0.5% of all youth) were identified with a primary ( $N = 52$ ) or comorbid ( $N = 19$ ) schizophrenia-spectrum disorder

at the time of their most recent diagnostic assessment, and no youth received more than one diagnosis within the schizophrenia-spectrum family. The distribution of schizophrenia-spectrum diagnoses was Psychotic Disorder Not Otherwise specified (N = 37, 52.1%), Schizophrenia (N = 13, 18.3%), Schizoaffective (N = 8, 11.3%), Schizophreniform (N = 4, 5.6%), Delusional Disorder (N = 4, 5.6%), Paranoid Personality (N = 2, 2.8%), Schizotypal Personality (N = 2, 2.8%), and Brief Psychotic Disorder (N = 1, 1.4%). The remaining 13,904 youth without a schizophrenia-spectrum diagnosis were included as a comparison group. The most common primary diagnoses in the non-schizophrenia-spectrum group were attentional (23.3%), disruptive behavior (12.1%), mood (10.2%), adjustment (9.5%), anxiety (6.1%), pervasive developmental (4.7%), and other disorders (5.3%). A small proportion of youth did not meet criteria for any diagnosis (0.9%) and primary diagnostic information was missing for 27.9% of the group. Additional description of sample demographics and analysis of comorbid diagnostic information is presented in the results section below.

After detailed analysis, a decision was made to include youth with missing primary diagnostic information (n = 3,879) in the non-schizophrenia-spectrum group. If the overall diagnostic distribution was comparable in this group with missing data, roughly 20 to 25 youth in the missing data group would be expected to have a schizophrenia-spectrum diagnosis. This independent variable pollution would tend to decrease the likelihood of finding difference between groups, but given the large size of the non-spectrum comparison group these erroneously classified cases would tend to have a minimal overall effect. The alternative of applying listwise deletion of all 3,879 cases (3,855 to 3,859 of which were expected to have no schizophrenia-spectrum diagnosis) would likely have a much larger overall biasing effect on group statistics and restricts the overall generality of the sample as a representation of the total

CAMHD system. Due to missing diagnostic data, the point estimates from this study should not be viewed as prevalence estimates within the CAMHD population, but the distributions of variables may be meaningfully compared between these groups and will tend to yield a conservative test of differences.

## **Measures**

Child and Adolescent Mental Health Information System (CAMHMIS) Fields. The primary data source for this report was the Child and Adolescent Mental Health Management Information System. Information was gathered and entered into CAMHMIS through the standard operating procedures of the regional Family Guidance Centers.

### Population Variables

Mental health care coordinators at the regional family guidance centers are responsible for gathering and updating data from families and professionals related to client demographics, diagnosis, and interagency involvement. Accurate completion of this information is managed through a variety of quality assurance activities and feedback mechanisms including statewide, on-demand reporting systems. The quality and availability of data varies across fields, and known data limitations are noted throughout the manuscript as illustrated by the primary diagnostic described in the participant section above.

Age in Years was defined as the difference between a youth's date of birth and June 30, 2001 (i.e., the final day of fiscal year 2001).

Agency Involvement data (i.e., Department of Human Services (DHS), court, and incarcerated/detained) were entered into CAMHMIS in the form of a start date and end date of involvement with each agency. A youth was defined as involved with a specific agency if they

had an active record with that agency that included a start date prior to the final day of the reporting period (e.g., June 30, 2001) without an end date prior to the period end.

Diagnostic Status was defined based on Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) codes entered into CAMHMIS. Youth registered with CAMHD receive annual diagnostic evaluations from the Department of Education (DOE), contracted providers, or occasionally CAMHD clinical staff. Interagency performance standards (Hawaii Departments of Education and Health, 2002) require service providers to include a five axis DSM-IV diagnosis in their summary report. Practice guidelines state that “clinicians are encouraged to use structured or semi-structured clinical interviews to arrive at a clinical diagnosis” (p. 160) but do not mandate a particular interview protocol. Diagnostic information included in the final evaluation report is entered into CAMHMIS. CAMHMIS maintains a historical record of all diagnostic events and includes fields for recording primary, secondary, and tertiary diagnoses on Axis I, and primary and secondary diagnoses on Axis II, as well as fields for Axes III - V. Diagnoses on either axis whether primary, secondary, or tertiary were included in analysis of comorbid diagnoses.

Ethnicity was based on client self-presentation and was coded directly in CAMHMIS as African-American, African Other, American Indian, Asian Other, Caucasian Other, Chamorro, Chinese, Filipino, Hawaiian, Hispanic Other, Japanese, Korean, Micronesian, Mixed Ethnicity, Pacific Islander Other, Portuguese, Puerto Rican, or Samoan. For some analysis, these categories are aggregated into the following groups: American Indian or Alaska Native, Asian, Black or African American, Hispanic, Multiethnic, Native Hawaiian or Pacific Islander, and White.

Family Guidance Center (FGC) was defined as the most recent center to which youth were registered as of the final day of the reporting period.

Gender was based on client self-presentation and was coded as either female or male.

#### Service Variables

Service variables were calculated based on records that were accepted as payable during billing adjudication for the hospital residential, community residential, therapeutic group home, therapeutic foster home, respite home, intensive day stabilization, partial hospitalization, day treatment, biopsychosocial rehabilitation, intensive in-home, intensive in-school, and less intensive levels of care. For atypical services that do not bill electronically through CAMHMIS (i.e., out-of-state, community high risk, multisystemic therapy, flex, and respite), service information was based on the CAMHMIS service authorization database and was augmented by information based on manually adjudicated billing processed by the CAMHD Fiscal Office and by weekly provider census data collected by the CAMHD Clinical Services Office.

Receipt of Service. A youth was identified as receiving a service if there was a record of payment for the service on at least one day during the reporting period. Thus, the service receipt counts are unduplicated within a level of care, but are duplicated across levels of care. For example a youth who received one month of hospital residential and two months of intensive in-home services would be recorded as receiving both of these levels during the reporting period.

Out-of-home Services was an indicator variable identifying if a youth received any out-of-home service during the period. Out-of-home services included out-of-state, acute inpatient, hospital residential, community high risk residential, community residential, therapeutic group home, and therapeutic foster home services. Regardless of type, services provided while a youth was detained or incarcerated were defined as an out-of-home service.

Intensive Home and Community Based Services was an indicator variable identifying if a youth received any intensive mental health service in the home, school, or community setting.

Intensive home and community based services included intensive in-home services, intensive in-school services, multisystemic therapy, biopsychosocial rehabilitation, day treatment, and partial hospitalization.

Less Intensive Services was an indicator of whether any assessment, consultation, or treatment services were provided on an outpatient basis. Assessment services included mental health assessments, psychosexual assessments, psychological testing, and psychiatric evaluations. Consultation services included activities such as participation in educational planning, treatment planning, and family court testimony. Treatment services included such services as individual, group, or family psychotherapy and medication monitoring.

Flex or Respite Services was an indicator of whether any flexibly funded or respite services were provided to the youth or family. Flexibly funded services include associated services, such as medication and transportation, as well as direct services that are not available through the standard service array. When direct services were comparable to a standard service provided through the CAMHD network, they were coded in the standard service category, even if they were flexibly funded. For example, a community residential program provided outside of the CAMHD network would be counted as a community residential service and not as a flex service, even though funded through a flex benefit. Respite services involved allocation of funds to pay for care of the youth to relieve the family of responsibility for the child for a circumscribed period of time.

Total Cost of Services was the sum of all direct service expenditures (US\$) recorded during the study period. The vast majority of CAMHD services were funded through unit rate contracts. The unit rates were defined to reimburse providers for both direct and indirect costs. However, these costs do not include CAMHD's general administrative expenditures to maintain

the state administrative offices and the regional family guidance centers through which case management services were provided. For services provided through other contracting arrangements (e.g., cost reimbursement contracts), total expenditures were allocated based on service authorizations as noted above.

### **Procedures**

Upon receipt of a referral to CAMHD, client cases were assigned to care coordinators to provide case management services. Care coordinators were responsible for assembling interagency family treatment teams, preparing coordinated service plans, arranging for appropriate services, and administering child status assessments. When arranging services, care coordinators worked with families and teams to select appropriate services from within the CAMHD service array. When needed services were not available within the standard CAMHD array, care coordinators could arrange to procure customized services through the flex benefit. Mental health supervisors provided administrative and clinical supervision for care coordinators. Each regional family guidance center also had a supervisory team(s) that, while diversely organized, generally consisted of some combination of a branch chief, psychiatrist, psychologist, and/or quality assurance specialist that provided concurrent review, quality improvement, and practice development activities.

### **Data Analysis**

Data were analyzed using one of two strategies. First, chi-square tests were used with frequency count variables (e.g., gender, service receipt, etc.) to test the null hypothesis that cases were randomly distributed across the spectrum and non-spectrum groups. Second, one-way between groups Analysis of Variance (ANOVA; a.k.a.,  $t^2$  tests) was used with ratio-scaled variables (i.e., age, number of diagnoses, and total expenditures) to test the null hypothesis that

means were equivalent across the spectrum and non-spectrum groups. An alpha of .05 was used for all analyses unless otherwise indicated. Additional alpha correction was not performed because tests were generally expected to be somewhat conservative due to the inclusion of cases with missing primary diagnostic information in the control group.

## Results

### Population Findings

#### Demographic Characteristics

The first set of analyses examined the age, gender, ethnicity, interagency involvement, and geographic distribution of youth with schizophrenia-spectrum disorders compared to all other youth served by CAMHD. Analyses indicated that schizophrenia-spectrum and non-spectrum groups were not significantly different in their gender and geographic distribution, but were different in age and ethnicity. Both groups were 70% male and 30% female,  $\chi^2(1, N = 13,975) = 0.002, p = .966$ , and represented all regional family guidance centers in the expected proportions,  $\chi^2(6, N = 13,975) = 7.57, p = .272$ . No significant differences were evident in the proportion of the groups involved with the Department of Human Services,  $\chi^2(1, N = 13,975) = 0.04, p = .840$ , or Family Court,  $\chi^2(1, N = 13,975) = 0.30, p = .583$ . The schizophrenia-spectrum youth,  $M = 14.6$  years,  $SD = 2.9$ , were significantly older than the non-spectrum youth,  $M = 12.0$  years,  $SD = 3.8, F(1, 13,973) = 33.37, p < .001$ .

Because reporting of race and ethnicity was optional, ethnic information was only available for a subset of youth (see Table 1), with the spectrum group (60.5%) having significantly higher completion rates than the non-spectrum group (46.9%),  $\chi^2(1, N = 13,975) = 5.28, p = .022$ . Although the ethnic distribution for youth with information available was generally similar across the spectrum and non-spectrum groups, the spectrum group included a

higher proportion of Asian youth than the non-spectrum group,  $\chi^2(1, N = 6,566) = 4.16, p = .041$ . This was balanced by a tendency for the spectrum group to include fewer Native Hawaiian or Pacific Islander youth, but this effect did not meet strict criteria for significance,  $\chi^2(1, N = 6,566) = 2.84, p = .092$ .

Table 1. Ethnic distribution of youth with and without schizophrenia-spectrum disorders.

Ethnicity	Spectrum		Non-Spectrum	
	n	% of Available	n	% of Available
American Indian or Alaska Native	0	0.0%	30	0.5%
Asian*	13	30.2%	1,186	18.2%
Black or African American	2	4.7%	161	2.5%
Hispanic	0	0.0%	127	1.9%
Multiethnic	15	34.9%	1,921	29.4%
Native Hawaiian or Pacific Islander <sup>+</sup>	6	14.0%	1,639	25.1%
White	7	16.3%	1,459	22.4%

Note: \*  $p < .05$ , <sup>+</sup>  $p < .10$ ; Spectrum  $n = 43$  available, non-spectrum  $n = 6,523$  available.

### Analysis of Comorbidity

Several analyses were conducted to describe patterns of diagnostic comorbidity in the spectrum and non-spectrum groups. First, a chi-square test was used to examine the proportion of youth with more than one diagnosis recorded. Second, an ANOVA was calculated to compare the average number of diagnoses in each group. Finally, a series of chi-square tests were calculated to compare whether the proportion of youth with any diagnosis (primary or comorbid) in each diagnostic category differed across groups.

Results indicated that the spectrum group experienced a higher rate of comorbidity whether indexed as a proportion with multiple diagnoses,  $\chi^2(1, N = 10,096) = 4.18, p = .041$ , or

as an average number of diagnoses,  $F(1, 10,094) = 11.61, p = .001$ . Specifically, 62.0% of the spectrum group received comorbid diagnoses and averaged 2.0 diagnoses per youth compared with 49.8% of the non-spectrum group averaging 1.7 diagnoses per youth.

Comparison of the prevalence of specific diagnostic categories revealed that the spectrum and non-spectrum groups did not significantly differ in the proportion of youth with other (22.5% vs. 22.8%,  $\chi^2(1, N = 10,096) = 0.002, p = .965$ ), mood (15.5% vs. 20.6%,  $\chi^2(1, N = 10,096) = 1.14, p = .286$ ), anxiety (8.5% vs. 12.4%,  $\chi^2(1, N = 10,096) = 1.00, p = .316$ ), pervasive developmental (2.8% vs. 6.8%,  $\chi^2(1, N = 10,096) = 1.75, p = .186$ ), or substance-related (1.4% vs. 5.2%,  $\chi^2(1, N = 10,096) = 2.05, p = .152$ ) disorders. The spectrum group was less likely than the non-spectrum group to receive diagnoses of attentional (14.1% vs. 42.6%,  $\chi^2(1, N = 10,096) = 23.52, p < .001$ ), disruptive behavior (15.5% vs. 30.2%,  $\chi^2(1, N = 10,096) = 7.21, p = .007$ ), and adjustment disorders (7.0% vs. 17.1%,  $\chi^2(1, N = 10,096) = 5.08, p = .024$ ), and more likely to receive a diagnosis of mental retardation (9.9% vs. 3.1%,  $\chi^2(1, N = 10,096) = 10.68, p = .001$ ). The five most common non-spectrum diagnoses in the spectrum group were other, disruptive, mood, attentional, and mental retardation disorders, compared with the attentional, disruptive, other, mood, and adjustment disorders in the non-spectrum group. Thus, although the rank ordering and point prevalence estimates were different the four most common diagnoses were similar in the spectrum and non-spectrum groups. Mental retardation was the fifth most common diagnostic category in the spectrum group and was more prevalent than in the non-spectrum group.

## Service Findings

### Type of Services Procured

All youth registered with CAMHD receive intensive case management services. Care coordinators organize interagency family treatment teams that jointly develop coordinated service plans specifying the treatment goals and identifying formal services and informal supports needed to reach those goals. Care coordinators then arrange for the purchase of planned services through the CAMHD provider network, or through flex funding if a customized service is needed. Service plans do not necessarily call for the purchase of additional services beyond intensive case management and informal supports. Examination of the proportion of youth with at least one service procured found that a higher proportion of youth in the spectrum group (87.3%) than in the non-spectrum group (77.2%) had services procured,  $\chi^2(1, N = 13,975) = 4.12, p = .042$ .

The next set of analyses examined whether the type of service procured (i.e., out-of-home, intensive home and community, less intensive, and flex or respite services) differed across groups for those youth with at least one service procured. Results indicated that the groups did not differ in their receipt of less intensive services,  $\chi^2(1, N = 10,795) = 0.01, p = .942$ , but a higher proportion of youth in the schizophrenia-spectrum group received out-of-home,  $\chi^2(1, N = 10,795) = 21.93, p < .001$ , intensive home and community,  $\chi^2(1, N = 10,795) = 4.61, p = .032$ , and flex or respite services,  $\chi^2(1, N = 10,795) = 30.33, p < .001$ , than the non-spectrum group (see Table 2).

Table 2. Summary of the type of services received by youth with and without schizophrenia-spectrum disorders in terms of the number and proportion of youth with services procured.

Service Category	Spectrum		Non-Spectrum	
	n	% of Procured	n	% of Procured
Out-of-Home*	14	22.6%	766	7.1%
Intensive Home & Community*	31	50.0%	3,951	36.8%
Less Intensive	59	95.2%	10,192	95.0%
Flex or Respite*	19	30.6%	1,045	9.7%

Note: \*  $p < .05$ ; youth may have received more than one type of service; spectrum group  $n = 62$  with services procured, non-spectrum group  $n = 10,733$  with services procured.

Detailed analysis of the out-of-home service array found that a higher proportion of youth in the spectrum group received hospital residential services (8.1% vs. 1.5%,  $\chi^2(1, N = 10,795) = 17.86, p < .001$ ), therapeutic group home (6.5% vs. 1.9%,  $\chi^2(1, N = 10,795) = 6.70, p = .010$ ), and therapeutic foster home (9.7% vs. 2.0%,  $\chi^2(1, N = 10,795) = 17.74, p < .001$ ). No significant differences were evident for out-of-state (1.6% vs. 0.5%,  $\chi^2(1, N = 10,795) = 1.66, p = .197$ ) or community-based residential services (1.6% vs. 2.3%,  $\chi^2(1, N = 10,795) = 0.15, p = .703$ ).

Within the intensive home and community array, a higher proportion of youth in the spectrum group received partial hospitalization (11.3% vs. 0.7%,  $\chi^2(1, N = 10,795) = 86.89, p < .001$ ), biopsychosocial rehabilitation (9.7% vs. 4.1%,  $\chi^2(1, N = 10,795) = 4.71, p = .030$ ), and intensive in-home services (29.0% vs. 13.8%,  $\chi^2(1, N = 10,795) = 11.90, p = .001$ ). The groups did not differ in receipt of day treatment (3.2% vs. 3.4%,  $\chi^2(1, N = 10,795) = 0.004, p = .949$ ), multisystemic therapy (3.2% vs. 2.7%,  $\chi^2(1, N = 10,795) = 0.07, p = .796$ ), or intensive in-school services (19.4% vs. 20.4%,  $\chi^2(1, N = 10,795) = 0.04, p = .832$ ).

Further analysis of the flex or respite category found that procurement of both flex (25.8% vs. 7.1%,  $\chi^2(1, N = 10,795) = 32.26, p < .001$ ) and respite (9.7% vs. 3.6%,  $\chi^2(1, N = 10,795) = 6.55, p = .010$ ) services were significantly more common for youth in the spectrum group than the non-spectrum group. Thus, proportionally more families of youth with schizophrenia-spectrum diagnoses received customized and adjunctive services and child care respite supports than families in the general CAMHD populations.

In-depth analysis of the less intensive service array, revealed that a higher proportion of youth in the spectrum group (93.5%) than the non-spectrum group (75.5%) received outpatient treatment services,  $\chi^2(1, N = 10,795) = 10.88, p = .001$ . The groups did not significantly differ in the proportion of youth receiving assessment (56.5% vs. 54.1%,  $\chi^2(1, N = 10,795) = 0.13, p = .714$ ) or consultation services (46.8% vs. 35.1%,  $\chi^2(1, N = 10,795) = 3.67, p = .055$ ).

#### Cost of Services Procured

The final set of analyses examined the average cost per youth for the different service categories. Cost per youth is a summary variable that is affected by the intensity, duration, and restrictiveness of care and therefore may serve as a proxy for these factors. Examination of cost per youth rather than total cost adjusts for the differences between groups in the number of youth receiving services. Overall analysis indicated that the average annual cost of services in the spectrum group (\$16,240 per youth) was significantly higher than in the non-spectrum group (\$8,931 per youth),  $\chi^2(1, N = 10,787) = 8.30, p = .004$ . Thus, youth with a diagnosis in the schizophrenia-spectrum consumed more financial resources in the form of services provided at a greater level of intensity, duration, or restrictiveness.

To further distinguish the restrictiveness cost driver from the intensity and duration cost drivers, analyses were repeated by type of service. Since the unit cost rates at each level of care

were equivalent for the two groups, significant differences in the average cost per youth across groups within service categories indicates that the groups differed in the intensity or duration of services received at the given level of care. Conversely, non-significant differences indicate that, when services were provided at the given level of care, youth in the spectrum and non-spectrum groups received a similar intensity and duration service. For the sake of convenience, findings are reported at the level of service category rather than discrete levels of care. The average annual cost per youth for out-of-home  $\chi^2(1, N = 700) = 1.38, p = .241$ , intensive home and community  $\chi^2(1, N = 3,963) = 0.52, p = .470$ , and flex or respite services  $\chi^2(1, N = 1,062) = 0.10, p = .748$ , did not differ between the spectrum and non-spectrum groups. The average annual expenditure per youth for less intensive services was greater in the spectrum (\$5,103) than the non-spectrum (\$3,123) group,  $\chi^2(1, N = 10,249) = 5.52, p = .019$ .

Taken together, findings from the service analyses indicated that a higher proportion of youth with schizophrenia-spectrum diagnoses received out-of-home, intensive home and community based, and flex or respite services, but when these services were provided they tended to be of a similar duration and intensity for youth with and without diagnoses in schizophrenia-spectrum. On the other hand, almost all youth (95%) in both groups received less intensive services, but youth in the schizophrenia-spectrum group received more treatment services at a higher intensity or longer duration than youth in the non-spectrum group.

### Discussion

The results from the current study suggest that youth with a schizophrenia-spectrum diagnosis registered for mental health services with the Hawaii Department of Health show a unique demographic and service-utilization profile relative to all other registered youth in Hawaii. Youth with schizophrenia-spectrum disorders were more likely to be older, of Asian

descent, and have a diagnosis of mental retardation. They were less likely to be diagnosed with disruptive behavior, attentional, or adjustment disorders. A higher proportion of youth with schizophrenia-spectrum disorders received out-of-home, intensive home and community based, and flex or respite services, but not less intensive services. As expected due to the provision of more restrictive services, the average annual cost of serving youth with schizophrenia-spectrum disorders was also higher. When service restrictiveness was controlled, the average annual cost per youth was comparable for all service categories except less intensive services. Average annual expenditures per youth for outpatient therapy were greater for youth with schizophrenia-spectrum disorders.

### **Participants**

Due to missing diagnostic data, the observed point prevalence (0.5%) of schizophrenia-spectrum disorders in the present sample is not a precise estimate of this true value. A more reasonable point estimate might be obtained by assuming that diagnostic data were missing randomly across groups, which yields a point prevalence of 0.7%. With the additional, rather extravagant, assumption that CAMHD registered all youth between 3 and 18 years of age with schizophrenia-spectrum disorders in the state, this would translate to a prevalence rate of 3.7 per 10,000 youth. Assuming an accurate diagnostic breakdown within the spectrum disorders (i.e., 18.3% of spectrum youth have schizophrenia), the estimated prevalence rate of schizophrenia would be 0.7 youth per 10,000. Although these prevalence estimates are *very* imprecise and based on *very* speculative assumptions, the CAMHD rate approximated the Renschmidt et al. (1994) estimate that 1 in 10,000 youth suffer from schizophrenia. As might be expected, the CAMHD analysis, which included home and community services, yielded a slightly lower prevalence rate estimate than that reported in a psychiatric in-patient population by Thomsen

(1996). Additionally, the low rate of schizophrenia-spectrum disorders at CAMHD was consistent with the generally accepted notion that these disorders are rare in youth (Jacobson et al., 1980). As previously noted, additional epidemiological data regarding prevalence of schizophrenia and schizophrenia-spectrum disorders in youth is needed. The present results provide general guidance as to the prevalence of these disorders within a specific public mental health system, but should *not* be used as valid population estimates.

Our finding that schizophrenia-spectrum youth were significantly older than non-schizophrenia-spectrum youth is also consistent with the finding that psychotic disorders typically arise in late adolescence and early adulthood. Similar to our findings, Thomsen (1996) reported an increase in rate of schizophrenia with age among youth. Beitchman (1985) suggested that schizophrenia occurs approximately 50 times more often after age 15 than before it. In the present sample 41% of youth in the spectrum group were less than 15 years of age and 59% were 15 years of age or older. Thus, the distribution was negatively skewed, but not to the extent reported in the general population.

The gender ratio of spectrum youth in the CAMHD sample (1 to 2.38) did not significantly differ from non-spectrum youth. This gender ratio conflicts with general prevalence estimates of adult schizophrenia that have suggested approximately equal gender distribution. The ratio of males to females with spectrum disorder from our study, however, fell within a range of estimates of schizophrenia among youth from previous studies (Beitchman, 1985; Evans & Acton, 1972). Kolvin and colleagues (1971) suggested that the predominance of males in youth with schizophrenia differentiates early schizophrenia from adult schizophrenia.

Although considerable research is still needed, examinations of gender differences in utilization of mental health services across diagnoses have described a pattern that evolves from

greater service utilization by males in childhood and early adolescence, through gender equality, to greater utilization by females in adulthood (c.f., Cuffe et al., 2001; Lindamer, Bailey, & Hawthorne, 2003). As seen within the spectrum and non-spectrum youth from the current sample, the predominance of males over females has been a consistent feature of the general CAMHD population across recent years (Daleiden, 2003).

Ethnic background did not significantly differ between the spectrum and non-spectrum groups, with the exception of Asian youth. Our findings indicated that Asian youth accounted for a larger proportion of the spectrum disorder group than the non-spectrum group. As is typical of the CAMHD population across years (Daleiden, 2003), the proportion of Asian youth in the non-spectrum group (18.2%) was less than the proportion of Asian youth (29.9%) in the general Hawaii population (U.S. Census Bureau, 2000). The proportion of Asian in the spectrum group (30.2%) more closely approximated the expected general population of youth in Hawaii. Several studies have found that Asian Americans have a lower representation in hospital-based and community mental health service populations than expected based on census estimates (e.g., Leong, 1994). Although the source of such underutilization is unclear, cultural stigma, unresponsive services, and increased reliance on informal supports have all been offered as explanatory hypotheses (e.g., Leong, 1994; Sue & Morishima, 1982). The closer approximation to census estimates in the group of youth with schizophrenia-spectrum disorders may indicate that the severity of spectrum disorders or a perception that schizophrenia-spectrum disorders have a physical health basis may account for the increased likelihood that Asian youth with spectrum disorders receive mental health services.

### **Analysis of Comorbidity**

Youth with spectrum disorders from our sample typically had multiple diagnoses. Disruptive behaviors and attentional problems were the most frequently diagnosed comorbid conditions for both youth with and without spectrum disorders. However, the rate of comorbid disruptive behavior and attentional problems among non-spectrum youth was significantly greater than among youth with spectrum disorders. This pattern of results suggests that youth with disruptive and attentional disorders are more likely to be registered with the Department of Health than youth with any other diagnosis, but this effect was not as pronounced for youth with schizophrenia-spectrum disorders. Consistent with previous reports (e.g., Aylward et al., 1984) suggesting a link between mental retardation and schizophrenia, youth with spectrum disorders were more likely to have a diagnosis of mental retardation than non-spectrum youth. According to Aylward and colleagues, mental retardation can serve as a premorbid feature of early onset schizophrenia.

### **Services**

The present study analyzed the type of services provided in terms of service setting or level of care. Service costs and core service system values, such as provision of services in least restrictive environments, make level of care a key variable of interest. Standardized systems for supporting level of care placement decisions tend to emphasize child safety and risk factors, problem complexity and severity, and environmental resources (e.g., American Academy of Child and Adolescent Psychiatry, 1999; Hodges, 1995). Accordingly, the above average use of more restrictive levels of care may reflect that youth with schizophrenia-spectrum disorders suffer from severe and complex problems that tax environmental resources and may promote risks to child safety. Alternatively, results from the service analyses suggest that approximately 4

out of 5 youth with services procured for schizophrenia-spectrum problems are managed in their home or community setting. Approximately one-half received intensive home and community services and nearly all youth received less intensive outpatient supports. Further, approximately one-third of youth and families received customized, flexible services and respite support.

Because the present study did not examine sequencing of services within the year, it is unclear whether the provision of flex and respite services preceded and possibly prevented use of more restrictive services or was associated with lower use of more intensive services. Another important limitation to the services analyses is that although levels of care provide important contexts (e.g., safe and supportive) in which change can occur, specific treatment practices are not uniquely associated with levels of care. This study neither provided information regarding the specific treatment practices employed, nor the efficacy of those practices. Care providers and researchers alike know very little about effective treatments for early onset schizophrenia (Asarnow & Asarnow, 2003). The above average use of more restrictive services would seem to highlight an opportunity for the identification or development of evidence-based strategies that support management of schizophrenia-spectrum disorders in home and community settings.

In addition to requiring more services, youth with spectrum disorders are financially expensive. The average annual cost per youth with a schizophrenia-spectrum disorder was \$16,420, a rate nearly twice as high as the average annual cost per youth without a schizophrenia-spectrum disorder. This finding was consistent with a host of related research reporting that schizophrenia is an expensive illness to manage, especially among young people (Cuffel, Dilip et al, 1996; Rothbard, Metraux, & Blank, 2003; Smith, Shah, Wright, & Lewis, 1995). Designing comprehensive and flexible treatments tailored to the needs of this unique population may effectively reduce cost of services.

**Limitations**

The current study suffers from several notable limitations. As previously indicated, the sizable amount of missing diagnostic information would tend to lead to under-identifying youth with schizophrenia-spectrum disorders. We therefore suspect that our analyses were conservative due to the current effects of 1) contamination of the non-spectrum group with a small proportion of youth with missing schizophrenia-spectrum disorders, and 2) less schizophrenia-spectrum subjects in the spectrum group than actually exist in the sample. Although clinical standards require the use of DSM diagnoses and practice guidelines recommend use of structured interviews, electronic records do not support analysis of what portion of the diagnostic data involved structured versus unstructured approaches. Although we are aware that some providers do use structured interviews, clearly some do not, and this may introduce some unreliability into the grouping analyses.

The two study groups were also very different in size. Although the sample size difference was addressed as much as possible in the statistical tests (e.g., unweighted means analysis), large differences in sample sizes can amplify biases associated with violation of test assumptions. The current analyses compared the group with schizophrenia-spectrum disorders to the average of all other youth receiving services. Within the general CAMHD population, many other relevant comparison groups could be extracted for meaningful future analyses (e.g., youth with pervasive developmental disorder, bipolar disorder, etc.).

The present study did not examine any child status indicators that describe whether youth's functioning has improved. Therefore, although the present study found that the majority of youth with schizophrenia-spectrum disorders were maintained in home and community settings, this does not indicate that the functioning of these youth was improving in this setting.

Similarly, no evidence was examined regarding whether out-of-home service provision was associated with child improvements. A comprehensive outcome measurement system was being developed during this study period, so insufficient data were available to support such analysis. The CAMHD outcome measurement system should allow detailed investigation client improvement in future years.

Another caution when interpreting these results is that fiscal year 2001 was selected to provide an indication of the population and services that were provided in a public mental health system offering a full array of outpatient, intensive, and residential services. Due to the major restructuring of the public health system and the transfer of less intensive services to the Department of Education School Based Behavioral Health (SBBH) program, these results should not be generalized directly to the current CAMHD population. Instead they broadly reflect expectations for the combined SBBH and CAMHD population as it currently exists.

### **Summary**

In summary, schizophrenia-spectrum disorders represent a relatively uncommon set of disorders in youth that, when identified, tend to be present in late childhood or adolescence. Youth with schizophrenia-spectrum disorders represent a group of special interest due to their above average expense and high risk for out-of-home placement. Nevertheless, the majority of youth with schizophrenia-spectrum disorders were provided services exclusively in home and community settings. Future research may fruitfully examine services and strategies that promote maintaining these youth in their homes and communities.

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